Qualitative research exploring the ecology of conversations during surgical informed consent
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Introduction:
When a child needs surgery, the parent(s)/guardian(s) go through a process of learning that is much more diffuse than portrayed in the literature. The literature presents one single informed consent conversation that neatly and tidily informs the family about the surgery. In reality, there is a process of learning that starts when a family realizes that something is wrong with their child, continuing through the surgical consultation and meeting with several members of the surgical staff, through pre-operative visits and testing, often circling back to surgical staff with more questions, until the day of surgery when the informed consent form is ultimately signed and the surgery is performed. In addition, there is the post-operative period and recovery, and more questions and issues may still arise during that period.

The big question is: what does the family expect out of the experience? And how does this expectation match what actually occurs? The difference between expectation and reality is the gray space where problems occur. Misunderstandings, unexpected complications, unexpected side effects or outcomes can all lead to misaligned expectations.

Our review of the literature, preliminary research, and ongoing team discussions for our project has led to many significant questions about the informed consent process and how this affects patient/family expectations of surgery. One important issue, and one we aim to explore in this research, is the ecology of conversations around informed consent – across time, across providers, and across locations. In other words, how do families come to understand the surgery their child is about to receive? What is their process like?

Methods:
Two focus groups, each composed of 6-8 parents/guardians of children who received surgery through the Department of General Surgery at Boston Children's Hospital within the past year, will be convened in February 2016. The focus group guide, carefully developed with input from the research team, family faculty and some members of the hospital Family Advisory Committee, asks directly about parent's interactions with surgeons and nurse practitioners, such as: what communications led to understanding?; what led to confusion?; who did they go to with questions?; did they feel empathy from their providers?; did they understand the informed consent process?; what were their expectations of the surgery?; were their expectations met?

The focus group recordings will be transcribed verbatim and analyzed utilizing qualitative techniques. We don't have preconceived expectations and are open to the parents' experience. Themes that emerge from the data will be described with examples of parent quotes related to each theme.

Discussion/implications
The larger goal of our project is to improve the informed consent process for families whose children are considering surgery, and to train surgeons and other surgical providers to have better communication and relational skills. Asking parents directly about their experience with surgical consultations and with the informed consent process will add to the body of knowledge about family experience during this critical time, and will lead us forward as we develop trainings for surgical providers to improve these processes.